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Dyadic spousal experiences of Alzheimer's disease:
Marital satisfaction, caregiver burden, and coping

by

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A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Major: Human Development and Family Studies

Program of Study Committee:
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CHAPTER 1. INTRODUCTION

According to the most current Alzheimer's Association Facts and Figures report (2007), 5.1 million citizens are afflicted with Alzheimer's disease (AD) in the US population today. This number is projected to increase over the next 40 years to three times this amount (Brinton & Yamazaki, 1998). In the last thirty years, the number afflicted with AD has already doubled. Knowing such statistics supports a case for maintaining advocacy in the fight against AD. As this population of afflicted seniors continues to rise, so too does the awareness that this mentally degenerative disease affects more than just the person diagnosed. Increasingly we are seeing the negative effects AD has on the spouse and family watching the deterioration of their loved one (Marks, Lambert, & Choi, 2002). Research on caregiver burden has tremendously increased the awareness of the decline in general well being associated with becoming a caregiver (Allen, Blieszner, & Roberto, 2000). Response to this awareness is demonstrated not only through the increased literature found in journals but also the community resources provided for affected individuals. According to the US Department of Health and Human Services Administration on Aging (2003), there are caregiver support groups and respite care available to provide caregivers a break from the demands of caring for their loved ones. For those living with AD themselves, many of the caregiver respite options offer cognitive stimulation at the same time. Adult day care centers are one example.

Knowing AD affects a variety of people beyond the afflicted, it is increasingly pertinent to understand the importance of the family system when envisioning the optimal means of support for those with Alzheimer's disease. Research supports the assumption that as one increases in age, social supports are increasingly important to one's well being

(Holmen & Furukawa, 2002). Without the support of one's family, it is less likely that one will be able to function both socially and physically for long, especially in the face of deteriorating mental health due to AD. Family systems theory can be used to better understand the many factors affecting the progression of Alzheimer's disease and its effect on the family. Family systems theory encourages one to consider the levels of social systems one is embedded in and how they are connected (Whitchurch & Constantine, 1993). These systems include the spousal dyad, the family, one's community, and extend out to the broadest system of one's larger society.

There are many added benefits of treating AD from a systems perspective. By considering factors outside the individual, one has the potential to draw upon the strengths of multiple resources. No longer is the emphasis built solely around how individuals maintain their cognitive abilities and what they can do to ensure the slowest possible decline. A systems perspective allows one to draw upon the strengths of the spousal interaction, the shared experiences with others, and considers how each system can be maximized to work with the individual to promote inhibited mental decline (Qualls, 2000).

The use of a systems perspective in viewing treatment of Alzheimer's disease identifies Marital and Family Therapy (MFT) as one possible therapeutic approach. MFT generally maintains the perspective that change, growth, and healing occurs when all possible participants in a system are considered and included in the therapy process (Framo, 1982). This approach is thought to create a longer lasting effect when multiple people are included and simultaneously work toward a common goal of change (Nichols & Schwartz, 2004). By bringing multiple individuals together, the option for more perspectives to be addressed becomes possible. This provides a promising alternative to the current norm of Alzheimer's

patients working solely with facility staff and the spouses of Alzheimer's patients working with other spouses in support groups, a less optimal option than working with the immediate spousal dyad system by MFT perspectives (Qualls, 2000). If AD was addressed during a session with a marital and family therapist, it may be possible to accomplish many things unavailable to the spouses working separately to deal with the onset of AD. Marital therapists would be able to take on the role of educator and mediator and help the spouse learn healthy ways to cope and move beyond the grief and stress associated with watching a spouse deteriorate. By working with both spouses it would be possible to help the spouse not afflicted with AD to better deal with the changing states of cognition they observe in their partners.

An important element to consider in the approach of working with older couples is the time and context in which they grew up (Cooney & Dunne, 2001). The population afflicted with AD today has had very different experiences in their lifetime that impacts their relationship with the affliction. In general, research indicates that in the majority of healthy older adults many of the established therapeutic approaches will apply to treating older couples as it does to younger couples (Knight, 1999). However, this same research indicates that when specific aging issues such as Alzheimer's disease are present, one may need to adapt therapeutic approaches to accommodate these unique populations. Specifically in line with the major tenets of this study, it will be important to know exactly what people with AD and their partners see as important issues for a therapist to know prior to treatment. It will also be important to know how willing those same couples dealing with the effects of Alzheimer's disease would be to seek MFT services.

The purpose of this study was to specifically examine three domains that affect a spousal relationship in the presence of the progressive deterioration associated with Alzheimer's disease. The three domains are marital satisfaction, caregiver burden, and coping strategies. Concerning marital satisfaction, how do marital partners compare in marital satisfaction at different stages of the disease? Do those diagnosed with AD or their spouse rate higher in marital satisfaction between the disease stages? Are there gender differences that exist for the spouses of those diagnosed in marital satisfaction? Addressing caregiver burden, are there significant gender differences in caregiver burden that exist for the spouses of those diagnosed between the disease stages? Does one gender experience higher caregiver burden overall? Are there significant gender differences between the levels of burden reported between stages? Concerning coping, the purpose is to again compare those diagnosed and their spouses for coping abilities between the stages of the disease. Do those diagnosed with AD cope differently at different stages of the disease than their spouses? Does their style of coping significantly differ from one stage to the next?

The second purpose of this study was to explore the current resources that the spousal dyad is utilizing for the purpose of informing those who are new to the experience of working with this population. Understanding what resources these dyads are already using will allow those in the MFT field to better serve in the areas where resource voids still remain. What types of services do people of this population find particularly helpful in dealing with AD? Are there any services that the dyads recognize as unhelpful? Are there specific services that the dyads recognize as positively influential to their marriage? What types of services do the dyads identify as important but unavailable to them that would help them cope with the life changes associated with AD?

CHAPTER 2. LITERATURE REVIEW

Overview

The following literature review provides relevant information that has directed the path of this study. Provided here is an analysis of pertinent empirical evidence that relates to Alzheimer's disease and its potential effects on the spousal dyad. This review provides information regarding the basic tenets of marital and family therapy and its foundations in the systemic paradigm as it relates to marital satisfaction, spousal caregiver burden, and coping in the presence of a diagnosis of Alzheimer's disease in a marriage.

Alzheimer's Disease

The Alzheimer's literature portrays the progression of the disease as one that slowly strips afflicted people of their personality, function, and identity (Brinton & Yamazaki, 1998). The deterioration is associated with loss of neuron cells which carry messages throughout the brain. Initially, AD is known to impair the possibility for learning, memory, planning, and thought retrieval and ultimately inhibits one's speech, motor functioning, orientation, personality traits, and recognition skills. Alzheimer's disease cannot be diagnosed with complete certainty (Long, 2005). Generally speaking, the diagnosis is performed by ruling out other possible illnesses that are similar in nature to Alzheimer's disease. A definitive diagnosis is only possible postmortem by noticing plaque and tangle formation which are elements that disrupt the natural flow of vital nutrients to the nerve cells (Brinton & Yamazaki, 1998).

Presented with the facts and effects of AD on a person's daily functioning, it is not difficult to understand the urgency and threat that the disease poses to the affected individual. Common treatment options include medications that inhibit deterioration of the cells that

process the chemical messages of the brain. By inhibiting the breakdown of these chemicals, there is a chance that the medication will help compensate for the previous loss of the brain cells no longer able to process the messages traveling from one brain cell to the next (Long, 2005). Knight, Kaskie, Robinson-Shurgot, and Dave (2006) provided examples of other treatment options to include the use of memory training to sustain one's cognitive capacity and reality orientation to diminish confusion. The authors go on to say that it may be possible to use other psychotherapeutic approaches but only with the consideration of cognitive decline in place.

Building on the recommendation of Knight and his colleagues (2006), one may incorporate the use of a systems approach with treatment of AD. Literature by Pearce (2002) supports the idea that those who are afflicted by AD are not the only ones affected by its onset. As the progression of AD and the cognitive deterioration increases, those afflicted with the disease become more dependent on others to sustain daily living. Too often, those affected most directly beyond the persons diagnosed with AD are their spouses. Therefore, it is reasonable to speculate that a therapeutic approach to treating the emotional and practical aspects of AD should include at least the spouse in conjunction with those diagnosed with AD in the context of family therapy. In line with the study at hand, it is important to become more familiar with the specific changes that occur related to Alzheimer's disease and how they affect more than just the person diagnosed. By incorporating a means of accommodating everyone's experiences surrounding the illness, it is possible to foster an understanding of the illness for many people at once. Thus, it is important to understand specific elements of one's married life such as marital satisfaction, caregiver burden, and coping to be prepared for what changes may occur in the spousal dyad.

Family Systems Theory

Utilizing a systemic approach within treatment of Alzheimer's disease allows for the possibility to explore many aspects of the changing relationship within a spousal dyad not addressed through conventional treatment approaches. Family systems theory is based on the principle that the whole of a family is more than each individual added together (Nichols & Schwartz, 2004). Each person within a family is embedded within a multitude of different systems. A person exists within systems of family, peers, work and school, and even greater social systems such as the government. The interactions, conversations, response dynamics, and thoughts each person holds about one another in a family are influenced by these systems and in turn greatly influence how a family works.

The major shift in fundamental thinking provided by systems theory comes from the idea that problems arise outside of a person as opposed to individual psychotherapy beliefs that a person's problems are solvable if one looks internally (Pearce, 2002). By investigation of the larger system the family is situated in, it should be easier to understand how the family members obtain their viewpoints, which in turn affects how the family interacts. A family systems perspective also steps away from a linear view of a problem's progression. A linear view seeks to identify the A that causes B. Systems perspective breaks from this linear causality and investigates the many influences that may enhance a problem's existence through a circular process (Nichols & Schwartz, 2004). Such an approach avoids blaming any one person for the problem's existence and moves to find out how shifts in the family's structure may influence the problem (Nichols & Schwartz, 2004).

One of the chief tenets of family systems theory maintains that as a problem arises in the system, symptoms often occur with family members not directly connected with the

problem (Keeney, 1979). The idea that everyone in a family is ultimately connected and therefore affected by the interactions and experiences of others within the family relates well to an understanding of Alzheimer's disease. Numerous studies, for example, have been conducted on the effects of becoming a caregiver. As a family member's health deteriorates, other family members may assume more responsibilities and therefore experience financial, emotional, and physical burdens (Qualls, 2000).

A family system is also based around the roles and boundaries enacted by each individual family member in conjunction with one another. In the case of Alzheimer's onset, such roles and boundaries may shift as the one affected with the disease begins to deteriorate (Semel, 2006). Qualls (2000) reflected on the use of therapy with aging families when changes begin to occur in the decision making hierarchy. Such changes are inevitable when one experiences the cognitive deterioration associated with the onset of Alzheimer's disease. The author elaborated through discussion of how Salvador Minuchin's systemic approach of structural therapy is a possible means of helping families through the transition of altered boundaries and roles (Qualls, 2000). Structural family therapy is based on how families interact through patterns, and how such patterns maintain the presence of a problem (Nichols & Schwartz, 2004). By understanding and utilizing a family systems approach to working with the spousal dyad and their experiences of Alzheimer's disease, it is possible to make an impact that will last longer. In this study, a family systems approach is well suited to address marital satisfaction, caregiver burden, and coping as it facilitates an increased understanding between the couple of the changes that Alzheimer's disease brings about.

Systems Perspective and Marital and Family Therapy

The systems perspective is a fundamental foundation for the practice of marital and family therapy (Bockus, 1975). When considering how marital and family therapy is applicable to aging families, the literature reveals sparse and divided ideas about its application. In general, until the recent past there was not a great deal of attention devoted to how the practice of marital and family therapy can be used to work with aging families in our society. In a meta-analysis of the extent to which gerontological issues were represented in major marital and family therapy journals over a seven-year span from 1986 to 1993, Van Amburg, Barber, and Zimmerman (1996) found only 3.2% to be devoted to issues of aging. Furthermore, of the 3.2 % (or 28 articles), most were concerned with issues of caregiving and intergenerational conflict primarily in relation to how they affected the younger generations. More current research has increased the breadth of topics related to older couples as a response to the lack of literature and now includes research specific to intimate relationships, adult friendships, and diversity issues in older adults (Price & Brosi, 2006).

It is a step forward in the process of understanding older couples and their relationship dynamics that there is now a focus on family therapy and gerontology. However, it seems there is still a lag in the application of this information. For example, although this research now exists, it is rarely presented in journals associated with the MFT field. Evans (2004) presented one possible reason. The author indicated that older couples do not often seek therapy for marital issues possibly because of the differing ideas about what therapy was developed for, such as a mental illness, which may be a result of the historical perspectives they developed growing up. Another reason couples may not seek therapy is because of a lack of referral on the part of primary care providers. Evans cited possible reasons for this

second hypothesis as a result of ageism, which in this case stems from a belief that older couples cannot, should not, or will not be able to make changes to their relationship. In other words, clinicians impose their ideas of how older couples should interact and deny them the choice to seek help and make this decision for themselves. Ageism is the discrimination against someone based on the perception of their age (Palmore, 2003). The result of physicians not referring older individuals denies them a resource that they would be willing to use. For example, Knight et al. (2006) stated that research suggests older adults are no more reluctant to seek out therapy than younger adults.

Semel (2006) agreed with Knight's findings but added an important piece of information. The author noted that one must keep in mind the treatment may not need to be different between younger and older couples but it is imperative to understand there is a shift in content of issues. Older couples, for example, experience different transitions in the life cycle that, for some, are met with the complications of deteriorating health not common to their younger counterparts. Such life transitions more common to older couples include the transition to retirement, children moving out and starting families of their own, the death of one's parents, and possibly siblings. Every one of the issues listed has an impact on how a couple interacts, and thus it is important to realize some adjustments to such issues may not be easy for a couple to face. In this light, it seems important that marriage and family therapists be aware of such issues related to aging in order to apply a systemic approach to treatment.

The onset of a dementia such as Alzheimer's disease is one change that may need special attention when a therapist considers working with older couples. The changes that coincide with Alzheimer's disease in a relationship may hold the potential to lower marital

satisfaction in a marriage. For example, the roles that each spouse is so used to taking on may shift to accommodate the symptoms that accompany the illness progression and potentially create frustration and confusion. Without highlighting such issues and understanding such changes it is possible that marital dissatisfaction may contribute to other issues such as the inability to care for a spouse.

Marital Satisfaction and Alzheimer's Disease

Research concerning marriage in later life and its effect on satisfaction reveals that there are many factors that contribute to the potential for progressively lower satisfaction levels over the years (Umberson & Williams, 2005). Issues arise through health deterioration, retirement, and changes in family structure that pose a threat to men's and women's marital satisfaction in later life. Umberson and Williams (2005) reported that the threat is greatest for women as they tend to maintain a lower level of marital satisfaction throughout the life course compared to their male counterparts. It was hypothesized that this could be because of the differences in gender roles in society, which do not stop as one ages. The authors reported that women are more likely to face a spouse's deteriorating health sooner than their own as they tend to marry older men and live longer than their husbands. Umberson and Williams (2005) also stated that there is a correlation between satisfaction and health, meaning that as a married woman on average has a lower level of marital satisfaction this is linked to her poorer health. On a broader scale than marital satisfaction alone, Chipperfield and Havens (2001) reported that during a seven-year longitudinal study women were found to consistently report decreased life satisfaction whereas their male counterparts remained constant in life satisfaction. Given that the previously mentioned studies utilized participants who were not afflicted with an illness, it is important to note just how devastating the impact

of AD can be on a spousal dyad. If there are already reported findings that life satisfaction, at least for women, decreases over the life span, one can only imagine the devastating effects a diagnosis of a terminal illness would have on marital satisfaction.

The issue of marriage and the effects that Alzheimer's disease imposes upon it is not a very prominent topic in either general marital or gerontological literature. Most marital effects explored in concert with Alzheimer's disease focus on issues of caregiving and how the changing dynamics associated with caregiving increase the burden of the spouse. One such study was conducted by Gallagher-Thompson, Dal Canto, Jacob, and Thompson (2001) comparing the interaction patterns of spousal dyads where the husband does or does not have a diagnosis of AD. It was found that the diagnosis of AD had a significant impact on many dimensions of the marital relationship. The impact of the diagnosis included a significantly lower amount of communication between caregiving wives and their husbands with AD compared to spousal dyads not experiencing AD. The authors also found that wives in a caregiving role were significantly less encouraging of their husband's ideas, and husbands diagnosed with AD utilized fewer means of facilitation and support methods in conversation. Interestingly, though, the authors also reported that there was no significant difference in the amount of emotional closeness both populations of wives reported.

Wright (1998) reported through a longitudinal study of sexual intimacy and affection that spouses dealing with the diagnosis of Alzheimer's disease in one partner experienced a significant drop in the amount of affection and sexual intimacy experienced over a five-year period. Looking at these research studies together it is possible to draw the conclusion that at the onset of AD, many of the fundamental factors that define a romantic relationship such as sexual intimacy, affection, and supportive communication, are in potential danger. Further, it

is possible to infer then that when the fundamental factors of a relationship undergo change, there is great potential for discomfort and confusion between the spouses, which in turn adds to the daily stressors directly associated with Alzheimer's disease symptoms.

Although there are many studies that support the relationship between the experience of an affliction such as AD and its effect on relationship satisfaction, there is also evidence that marital satisfaction remains stable even in the presence of AD. Ott, Sanders, and Kelber (2007) found no significant difference in how satisfaction related to AD, the grief that may occur during the process, or the personal strain it may induce as related to marital satisfaction. Because such findings appear to contradict the impact AD has on marital satisfaction, further investigation is important.

Spouse as Caregiver

Caregiving arises as one of the most recognized and important issues when considering families in the context of Alzheimer's disease. Contrary to the pervasive myth that most aging individuals are left in nursing homes when an illness such as AD occurs, approximately 80% of the general population of disabled aging individuals receive primary care from their families (Neidhardt & Allen, 1993). With such a large number of citizens providing sometimes extensive care to family members, it is no wonder there is an abundance of studies looking into the caregiver's experience. The existence of a hierarchy has been found as to who fills the role of caregiver citing the spouse, if capable, as the first option to provide care (Dwyer, Henretta, Coward, & Barton, 1992). Knowing that the spouse is the default caregiver, it is important to understand how he/she is affected by the event of a spouse developing a disabling illness such as AD. Cavanaugh (1998) noted that spousal caregivers of those experiencing AD had increased psychological distress due to a shift in the

division of labor, shared responsibilities, and overall forced adjustments that occur to compensate for the symptoms of AD. The way caregivers respond to the caregiving experience allows further insight into the current reciprocal relationship the spouses are experiencing. Such knowledge may be helpful for a therapist to understand where adaptive and maladaptive changes now exist and how this affects the marital relationship.

A review of the literature reveals that both positive and negative experiences come out of assuming the role of caregiver, although the negative experiences are reported more often. Burton, Zdaniuk, Schulz, Jackson, and Hirsch (2003) reported findings from a five-year study following spouses into the caregiver role and found that, overall, the experience had deleterious effects on caregivers with a decrease in health behaviors, self reported health, and increased depression. Caregivers experiencing increased performance in the caregiver role over the years were also found to have higher indices of health problems and depression as the years progressed.

Evans (2004) supported the idea of using a systemic psychotherapy approach in order to ameliorate negative symptoms of caregiver burden. Working with a spousal dyad has the potential to motivate a shift in how one sees caring for the spouse and the initial resistance the spouse experiences due to imminent changes in the power structure and spousal roles in the relationship. Such roles may include underlying assumptions about gender and one's responsibilities in the relationship. Talking about changes that occur due to increased need for assistance performing activities of daily living may increase the likelihood of acceptance and ease of transition, thus alleviating some of the negative symptoms associated with caregiving.

One of the interesting variables associated with caregiving is that of gender of the spouse. Research findings support that women caregivers often experience a heightened sense of burden when compared to men caring for their wives (Barusch & Spaid, 1989). Taking into account the study conducted by Burton et al. (2003) that revealed caregiver burden increases over time and Barusch and Spaid (1989) who reported that there is a difference in caregiver burden by gender, it would be important to know if there is a significant gender difference between the burden level of spouses caring for those experiencing Alzheimer's disease at different stages of the disease.

Coping

How one copes at different stages of an illness is an important aspect to consider when working with spousal dyads experiencing Alzheimer's disease. McClendon, Smyth, and Neundorfer (2004) reported that the coping means used by caregivers were predictive of the rate of survival of their care recipient, specifically for those caregivers engaging in wishful-intrapsychic coping. Wishful-intrapsychic coping is associated with less active attempts to improve one's situation and a focus on thoughts of how one would like things to be different.

Specific to those diagnosed with AD, coping strategies can be problem-focused or emotion-focused (Fromholt & Bruhn, 1998). Problem-focused efforts are centered on compensating for the deleterious effects of the disease, whereas emotion-focused efforts involve increased efforts to reduce stress and anxiety associated with symptoms by seeking out personal relationship contacts. Pruchno and Resch (1989) expanded on the effects of problem and emotion-focused efforts reporting that within each effort there are different effects on different emotions of caregivers as well. Emotion-focused coping was associated

with alleviating depression and anxiety. Problem-focused efforts worked to improve positive affect. In general, the authors also reported that different coping strategies are effective for different issues that caregivers experience. Ott et al. (2007) found similar results associating use of problem-focused efforts with an increase in personal growth and also stated the importance of balancing such efforts with the use of emotion-focused coping.

Calasanti and King (2007) addressed the issue of gender and coping as it applied to caregiving spouses. The purpose of the study was to investigate how one understands gender roles and uses such knowledge to influence their approach to the role of spousal caregiving. The authors reported six approaches to caregiving embedded in the sense of what it means to be a man. The six approaches utilized by men most often were “exerting force, focusing on tasks, blocking emotions, minimizing disruptions, distracting attention, and self medicating” (Calasanti & King, 2007, p. 516). Hooker, Manoogian-O’Dell, Monahan, Frazier, and Shifren (2000) found that female spousal caregivers were less likely to use problem-focused coping efforts but both men and women caregivers were found to use emotion-focused coping efforts at similar rates. Lower use of problem-focused coping efforts was associated with high levels of distress.

Considering the findings of how coping styles affect both the caregiver and care recipient differently, it is important to take this fact into consideration when working with spousal dyads. More information is needed to know whether coping strategies are different between the stages of an illness such as Alzheimer’s disease and how this relates to gender of each spouse.

PURPOSE

The purpose of this study was to investigate the possible therapeutic needs of those afflicted with Alzheimer's disease and their spouses. Such findings will further the knowledge that those working in the field of marital and family therapy require to better serve such a population. As little research exists in context of what marital and family therapy can do for couples experiencing Alzheimer's disease, I set out to gain a preliminary understanding of what couples deem important when seeking assistance for understanding and dealing with the disease. Such knowledge is important as a gap remains in the literature about how clinicians should approach Alzheimer's disease. Generic therapeutic approaches may not be effective with this population and more information may be required in preparing to work with couples dealing with the onset of Alzheimer's disease.

Two general areas of research were encompassed in the project aims investigating how to apply marital and family therapy to the treatment of couples dealing with Alzheimer's disease. The first aim related to the understanding that Alzheimer's disease is a progressively degenerative disease. The investigation for this aim was to better understand the differences experienced by spouses dealing with AD when comparing those in the mild stage of AD and those in the moderate stage of AD. This aim was investigated through assessment of marital satisfaction, caregiver burden, and coping to find whether differences existed between the stages of the disease. It was predicted that marital satisfaction levels differed between the afflicted and their spouses at different stages of the disease. It was predicted that caregiver burden would be higher for women than for men. The coping section set out to define where differences existed between spouses in the use of coping strategies. It was predicted that women would use more emotion-focused coping strategies than men. Also, it was predicted

that non-afflicted spouses would use problem-focused coping strategies more than afflicted spouses. The second aim was to explore what current AD resources existed and where the gaps still remain. The aim was to better understand general expectations and needs of spouses dealing with the progression of AD. In other words, what is important for marital and family therapists to know about what couples expect and need from the therapist specific to AD?

CHAPTER 3. METHODS

Participants

Participants included 20 dyadic couples composed of one spouse diagnosed with Alzheimer's disease for a total of 40 participants. All participants were identified as white/Caucasian. Table 1 illustrates the means, ranges, and standard deviations for participant demographics.

Table 1

Demographic Information

Category	Minimum	Maximum	Mean	SD
Age	53	86	69.65	19.94
Marriage Length (years)	11	68	46.00	15.73
Education Length (years)	8	18	12.23	4.41
Income ^a	2	7	3.84	1.27
Children	0	5	2.78	1.27
Afflicted Subjective Health ^b	1	4	2.55	0.69
Spouse Subjective Health ^b	2	4	2.95	0.51
Caregiver Burden Score ^c	0	45	21.70	13.34
Afflicted Activities of Daily Living Score ^d	27	39	34.60	3.91
Spouse Activities of Daily Living Score ^d	24	39	37.90	3.46

Note. ^a 2 = \$10,000 - \$20,000, 3 = \$20,000 - \$40,000, 4 = \$40,000 - \$60,000, 5 = \$60,000 - \$80,000, 6 = \$80,000 - \$100,000, 7 = greater than \$100,000

^b 1 = poor, 2 = fair, 3 = good, 4 = excellent

^c n = 20. Highest score possible is 88, representing greater burden.

^d Highest score possible is 39, representing greater daily activity capability.

Participant occupations varied widely from unskilled laborer to professional. Occupation examples included babysitter, civil engineer, fire fighter, laundry worker, mail carrier, professor, registered nurse, sheet metal worker, teacher, and truck driver. Table 2 summarizes participant religious affiliation. Fifty percent of participants were Lutheran or Methodist.

Table 2

Religious Affiliation

Category	<i>n</i>	%
Lutheran	10	25.0
Methodist	10	25.0
Catholic	6	15.0
Christian	5	12.5
Protestant	4	10.0
None	3	7.5
Baptist	2	5.0

Thirty participants reported one marriage whereas the other 10 reported a second. Nine couples included a male spouse experiencing Alzheimer's disease and 11 couples with a female spouse experiencing AD. Eleven of the afflicted spouses were assigned to the mild category for cognitive impairment and nine were assigned to the moderate category. Categorization was based on the Mini Mental Status Exam score performed by a neuroscience physician. Although the literature cites cognitive impairment as a score of 22 or below (Folstein, Folstein, & McHugh, 1975), the categories were created by dividing the participant scores in half. This was done even though it did not fall in line with the original MMSE literature as the participants in this study were all diagnosed with cognitive

impairment by a physician despite higher MMSE scores. Couples experiencing cognitive impairment reported seeing a neuroscience physician for as long as 5 years and as recently as 2 months, with all receiving a specific diagnosis from a neuroscience physician. The amount of time under the neuroscience physician's care did not correspond to the level of cognitive impairment. Most couples (84%) reported experiencing an array of concurrent illnesses beyond dementia. Such illnesses are not confined to the spouse afflicted with AD and included diabetes, leukemia, heart problems, arthritis, high blood pressure, cholesterol, and asthma.

Spousal dyads were recruited through direct contact with a neuroscience physician at a medical center in a Midwestern state. All participants were referred to the neuroscience physician and memory clinic through their primary care physician. Potential participants were made aware of the opportunity to participate during their appointment. Those dyads with one spouse in a long-term care facility were excluded from the current study. They were unlikely to be able to benefit from the memory clinic as this population is often in the most progressive stages of AD when residing in a care facility. Couples who were visiting with the neuroscience physician for the first time and who did not yet have a Mini Mental Status exam score or diagnosis were also excluded. Without such information as the MMSE and diagnosis, these couples could not be categorized for analysis.

The sample was difficult to recruit because of time constraints of the participants while visiting the memory clinic; they often had appointments with other professionals involved with the memory clinic in the same day and many traveled from out of town. The fact that this is a special population may have compromised the sample size of this study.

Procedures

Patients of the memory clinic first saw the physician for a neurological check-up and during this appointment were apprised of the potential to participate in a research study about memory problems. If initially interested, the couple was brought to a private room and received a more in-depth introduction to the study from the principal investigator. Upon expressing interest to participate, both spouses were presented with informed consent forms to sign after reviewing them all together. The consent forms included permission to obtain the Mini Mental Status Exam score from the physician for categorization purposes. All forms and procedures were approved by the Iowa State University Institutional Review Board as shown in Appendix A. Before the spouse afflicted with AD signed the forms the investigator checked to see that they still maintained legal ability to sign for themselves. If there was another party that represented them other than their spouse, the couple was eliminated from the study.

Once consent forms were signed, participants were instructed to fill out a packet of survey questionnaires. Spouse with memory problems were given the choice of filling out the packet on their own or being assisted by the principal investigator. If participants opted to have help, the principal investigator read the questions aloud and the participants pointed to the phrase in the key of each questionnaire that best fit their experience. Discussion was discouraged between spouses by reminding them that their responses did not need to match and what they chose to answer was a good response. This was done to ensure confidentiality of each spouse's answers. To further ensure confidentiality, couples were spaced apart in the research room to discourage spouses from looking to see how the other answered. If the afflicted spouses were apprehensive about filling out the packet, the researcher assisted them

and had them point to their answers rather than speak aloud and reveal their answers to the spouse.

Upon completion of the packets the participants took part in an audio-taped interview concerning resources and services related to memory issues. The interview included both spouses to assess the individual and couple experiences. Once the interview was completed the couple was thanked and taken to their next memory clinic appointment. Altogether the procedure took an average of one half hour.

Measures

The data collected via survey questionnaire packets contained a demographic questionnaire and three standardized assessments, the Dyadic Satisfaction Sub-Scale (DSS), the Caregiver Burden Interview (CBI), and the Brief Cope. The interview pertained to Alzheimer's onset, diagnosis and current services related to Alzheimer's disease, and services the participants would like but did not currently have. The section pertaining to the effects of AD on the marriage was introduced with care emphasizing the strength of the marriage so as not to imply any marital discord was suspected. All assessments are included in Appendix B.

Dyadic Adjustment Scale-Dyadic Satisfaction Subscale. The first assessment was a subscale of a larger scale measuring marital satisfaction. The Dyadic Satisfaction Subscale of the Dyadic Adjustment Scale (Spanier, 1976) was used for this assessment. The Dyadic Satisfaction Subscale (DSS) is a 10-item scale with a possible scoring range from 0-50. Two of the ten questions were reverse coded. A higher score related to a higher level of dyadic adjustment. For example, a score of 4 on the question of how often one kisses his/her mate indicates that the couple expresses such affection every day. The DSS is scored on a 6-point

Likert scale for eight questions, a 7-point Likert scale for one question, and a 5-point Likert scale for one question. Spanier (1976) reported the criterion validity to be highly significant through the analyses of married vs. divorced couples' scoring. Construct validity was established through the comparison of the DSS with the already established Locke-Wallace Marital Adjustment Scale ($r = .86$). Reliability was assessed through the use of Cronbach's alpha and was found to be at .94 for the Dyadic Satisfaction Subscale and .96 for the entire Dyadic Adjustment Scale. In this study, one of the ten items was excluded from the analyses in order to increase the reliability level to .66. The item excluded was, "how often do you think that things between you and your partner are going well?"

Caregiver Burden Interview. The second assessment was the Caregiver Burden Interview (Zarit, 1986). The CBI is a 22-item scale with two subscales of personal strain and role strain. The responses are provided on a 5-point Likert scale, one being "never" to five being "nearly always," and the results are scored by adding the individual items with a higher score indicating that more caregiver burden is present. For example, "do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?" appears in the CBI. Higher scores indicate more burden with a scoring range of 0 to 88. Reliability for the entire scale was reported by Zarit (1986) using Cronbach's alpha to be .88, and for the subscales of personal strain and role strain the alpha levels were .80 and .81, respectively. Validity is reported through comparison of the CBI with the Brief Symptom Inventory at .71. The reliability of the CBI for this study was .91.

Brief Cope. The third assessment was the Brief Cope assessment (Carver, 1997). The Cope is a 28 item assessment with 14 subscales. The subscales are "self-distraction," "active coping," "denial," "substance use," "use of emotional support," "use of instrumental

support,” “behavioral disengagement,” “venting,” “positive reframing,” “planning,” “humor,” “acceptance,” “religion,” and “self-blame.” Higher scores within each subscale represented more use of that particular style of coping. Scoring is on a 4-point Likert scale, one being “I usually don’t do this at all” to four being “I usually do this a lot.” Each subscale is scored independently of one another for the purpose of finding which specific means of coping one uses, with a scoring range of 2-8. An example of one item on the Brief Cope is, “I’ve been giving up the attempt to cope.” Reliability of each subscale was reported through use of Cronbach’s alpha and all were above .60, except for mental disengagement, which was reported at .45. The authors report this is to be expected as the material associated with mental disengagement combines multiple actions (e.g., daydreaming, sleeping more, watch TV to think about it less, turn to work). The analysis involving the Cope subscales were performed using only the subscales that provided reliability greater than .5 for this study. Of the original fourteen subscales, eight provided an acceptable reliability score (Table 3). The eight subscales utilized were substance use, emotional support, venting, planning, humor, acceptance, religion, and self-blame.

Table 3

Cope Subscale Reliabilities

Subscale	Cronbach's Alpha
Active Coping	.04
Behavioral Disengagement	.39
Denial	.39
Instrumental Support	.40
Self Distraction	.43
Positive Reframe	.47
Acceptance	.61
Emotional Support	.61
Planning	.64
Humor	.71
Venting	.76
Substance Use	.78
Self Blame	.78
Religion	.85

Demographics and subjective health. The demographic questionnaire gathered the following information about the couple: age, ethnicity, gender, length of marriage, education, occupation (current or previous if retired), income level, and religious affiliation. The demographic portion also gathered information pertaining to each spouse's current level of physical functioning by assessing subjective health and one's ability to complete activities of daily living.

Interview. The interview questions gathered the following information: date of diagnosis, who made the diagnosis, concurrent illnesses of both spouses, services currently used individually and as a couple, level of helpfulness of services in use, past services and

reason for discontinuation, and services not received or available that the spouse would like to see available. All interviews were audio-taped. Interview questions are included in Appendix B.

Mini Mental Status Exam. The Mini Mental Status Exam (Folstein et al., 1975) was utilized to determine which AD stage each participant was experiencing. The exam was administered by the neuroscience physician and relayed to the primary investigator. The Mini Mental Status Exam (MMSE) has a maximum score of 30 points. Higher scores note less cognitive decline. For this study, scores were classified into two stages of impairment as follows: a score of 26 to 30 indicates mild cognitive impairment and 25 and below moderate impairment. The lowest score for cognitive impairment seen was 15. This type of categorization was done even though it did not fall in line with the original MMSE literature as the participants in this study were all diagnosed with cognitive impairment despite higher MMSE scores. Validity of the MMSE was reported through comparison with the Wechsler Adult Intelligence Scale, a standard cognitive test, and both verbal and performance scores were compared (Folstein et al., 1975). The scores were determined to have a Pearson correlation of .78 and .66, respectively. Reliability in the same study was tested using the Wilcoxon T, and a Pearson correlation of .83 was found. The current study did not have access to individual MMSE items and so the Cronbach's alpha could not be computed.

Data Analysis

Analysis of the data collected included descriptive statistics, paired t-tests, ANOVAs, and correlations for the quantitative data. Descriptive data analyses included frequencies and means related to the demographic information provided. Data analysis pertaining to the assessments included: 1) 2 (Stage) x 2 (Diagnosed or Spouse) ANOVA testing for the effect

of marital satisfaction by stages; 2) 2 (Stage) x 2 (Diagnosed or Spouse) ANOVAs were computed for each Cope subscale testing differences in one's ability to cope between those afflicted with Alzheimer's disease and their spouses; 3) 2 (Stage) x 2 (Gender) ANOVA was computed for differences between men and women non-afflicted spouses on marital satisfaction; 4) 2 (Stage) x 2 (Gender) ANOVA was computed to test differences in gender of spouse for burden; and 5) 2 (Stage) x 2 (Gender) ANOVAs were computed for each Cope subscale testing the effects of gender in the non-afflicted spouse's ability to cope with Alzheimer's disease.

Information provided through the interviews pertaining to services and resources for Alzheimer's disease was analyzed to find preliminary common themes that emerged from the participant responses that would have the potential for influencing a clinician's approach to working with this population.

CHAPTER 4. RESULTS

Overview

The results of the study provided unique insight into the experiences of the spousal dyad affected by Alzheimer's disease. What follows is the analysis of the data gathered from the packet of questionnaires including results of analysis on marital satisfaction, caregiver burden, and coping. Supplemental findings of the interviews are also provided.

Standardized Assessments

Data analysis of the information gathered from the Dyadic Satisfaction Sub-Scale, the Caregiver Burden Index, and the Cope subscales was carried out using SPSS for Windows.

Paired t-tests. Table 4 summarizes the results of the paired-samples *t*-tests for comparison of the afflicted spousal and the non-afflicted spousal means for each scale. The caregiver burden scale is not included in this analysis because only the non-afflicted spouse completed this scale.

The paired-samples *t* test for the DSS indicated that the mean satisfaction score for the afflicted spouse ($M = 38.00$) was not significantly different than the score of the non-afflicted spouse ($M = 37.30$). The scores obtained for the Activities of Daily Living Scale indicated that there was a significant difference between what afflicted participants were able to do versus their non-afflicted spouse. Spouses provided a significantly higher mean ($M = 37.9$) than their partners ($M = 34.6$) indicating a higher level of daily functioning. The Cope subscale analyses indicated there were two subscales with statistically significant findings. The Humor subscale showed a significant difference between the afflicted spouse ($M = 4.6$) and non-afflicted spouse ($M = 2.85$), with the afflicted spouses utilizing humor more often on average than their spouse. A significant difference was found between the non-afflicted

spouse ($M = 4.7$) and the afflicted spouse ($M = 5.8$) in seeking out emotional support as a means of coping. Non-afflicted spouses sought out emotional support as a means of coping significantly less often than their afflicted partners. The coping strategies utilized most often by the non-afflicted spouse were turning to religion, planning, and acceptance. Afflicted spouses utilized acceptance, planning, and turning to religion more frequently. When each spouse subjectively rated their current health, a significant difference was reported between scores. Afflicted spouses rated their health lower ($M = 2.55$) than non-afflicted spouses ($M = 2.95$).

Table 4

Paired Sample t-test Results between Spouses

Scale	Range	Afflicted (M)	Spouse (M)	t
Dyadic Adjustment Scale	0-45 ^a	38.00	37.30	1.03
Activities of Daily Living Score	0-39 ^b	34.60	37.90	-2.22*
Cope				
Substance Use	2-8 ^c	2.20	2.10	0.62
Emotional Support	2-8 ^c	5.80	4.70	1.99*
Venting	2-8 ^c	4.35	3.60	1.80
Planning	2-8 ^c	6.40	5.65	1.38
Humor	2-8 ^c	4.60	2.85	3.32**
Acceptance	2-8 ^c	6.85	5.20	1.83
Religion	2-8 ^c	6.35	6.30	0.11
Self Blame	2-8 ^c	4.15	3.40	1.83
Subjective Health	1-4 ^d	2.55	2.95	-2.63*

^a Higher scores indicate greater marital satisfaction

^b Higher scores indicate higher functioning level

^c Higher scores indicate greater use

^d Higher scores indicate better subjective health

$n = 20$

* $p < .05$. ** $p < .01$.

Analyses of Variance. Table 5 summarizes the results of the following findings related to stage of cognitive impairment and differences between the afflicted and the spouse. The 2 (Stage) x 2 (Diagnosed or Spouse) ANOVA revealed that the main effect of differences in marital satisfaction between mild ($M = 37.88$) and moderate ($M = 37.44$) cognitive impairment was not significant, $F(1,38) = .29, p = .60$. There was also no significant main effect for the diagnosed ($M = 38.00$) or the spouse ($M = 37.30$), $F(1, 38) = .09, p = .76$ in marital satisfaction. There was no significant interaction effect $F(1,38) = .13, p = .73$. The 2 (Stage) x 2 (Diagnosed or Spouse) ANOVAs for each Cope subscale testing differences in one's means of coping between those afflicted with Alzheimer's disease and their spouses found a significant difference in two of the subscales. The humor subscale results again showed that the afflicted spouse ($M = 4.60$) is significantly more likely to utilize humor as a coping strategy than the non-afflicted spouse ($M = 2.85$), $F(1,38) = 9.75, p = .003$.

The acceptance subscale showed a significant difference between the mild ($M = 5.23$) and moderate ($M = 7.0$) stages, $F(1,38) = 4.67, p = .037$. Such a finding showed a higher use of acceptance coping among those in the moderate stage of cognitive impairment. The acceptance subscale also demonstrated a difference in use between those afflicted ($M = 6.85$) and their spouse ($M = 5.30$) that approached significance $F(1,38) = 3.45, p = .07$. The afflicted spouses showed a higher use of acceptance as a coping strategy than their spouse. Between the two categories of stage and affliction or spouse, a significant interaction effect was also found $F(1,38) = 4.3, p = .045$ for the acceptance subscale.

Figure 1 illustrates the interaction effect. Whereas there is a significant difference between the afflicted and their spouse in the use of acceptance coping in the mild stage of impairment with the afflicted using the acceptance strategy more, at the moderate stage of

Table 5

Mean Differences for Cognitive Impairment Level and Couple Position (Afflicted or Spouse)

Scale	Impairment Level			Afflicted (A) or Spouse (S)			CIxAS
	Mild (<i>M</i> = 27.27)	Moderate (<i>M</i> = 22.11)	<i>F</i>	A	S	<i>F</i>	<i>F</i>
Dyadic Adjustment Scale	37.88	37.44	0.29	38.00	37.30	0.09	.13
Cope							
Substance Use	2.05	2.28	2.27	2.20	2.10	0.43	0.00
Emotional Support	4.86	5.72	2.06	5.80	4.70	3.35	0.68
Venting	3.77	4.22	0.87	4.35	3.60	0.13	0.17
Planning	5.77	6.33	0.99	6.40	5.65	1.76	1.46
Humor	3.50	4.00	0.77	4.60	2.85	9.75*	0.16
Acceptance	5.23	7.00	4.67*	6.85	5.20	3.45 ⁺	4.30*
Religion	6.00	6.72	1.38	6.35	6.30	0.01	0.32
Self Blame	3.73	3.83	0.04	4.15	3.40	1.85	0.45

⁺*p* < .1. **p* < .05. ***p* < .01.

impairment spouses of the afflicted tended to utilize acceptance coping with similar frequency to the afflicted spouse.

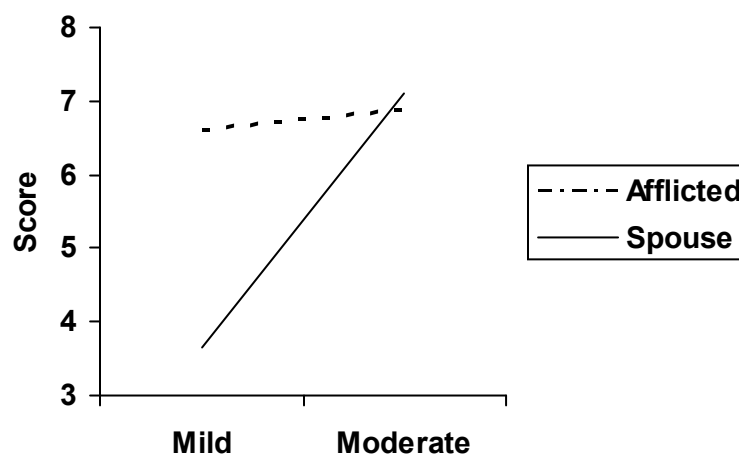


Figure 1. Differences in use of acceptance coping strategy of afflicted and spouse between mild and moderate stage.

Table 6 summarizes the findings related to the stage of cognitive impairment and gender for the non-afflicted spouses. Only the non-afflicted spouses were included in these analyses. The 2 (Stage) x 2 (Gender) computed for differences by gender of spouse not diagnosed in marital satisfaction provided significant results. Non-afflicted male spouses ($M = 39.59$) were found to report significantly higher marital satisfaction than non-afflicted female spouses ($M = 34.45$), $F(1, 16) = 14.89$, $p = .001$. The 2 (Stage) x 2 (Gender) ANOVA testing for differences in caregiver burden levels between the male and female spousal caregiver provided results that approached significance revealing that women ($M = 28.01$) showed a higher level of caregiver burden when caring for their afflicted husbands than men ($M = 17.7$) caring for their afflicted wives, $F(1, 16) = 3.68$, $p = .07$.

Table 6

Mean Differences in Spouse for Cognitive Impairment and Gender (Non-Afflicted Spouses Only)

Scale	Impairment Level			Gender			CIxG
	Mild	Moderate	<i>F</i>	Male	Female	<i>F</i>	<i>F</i>
DSS	36.46	37.58	0.70	39.59	34.45	14.89**	0.35
Caregiver Burden	18.32	27.42	2.85	17.70	28.01	3.68 ⁺	0.14
Cope							
Substance Use	2.00	2.25	1.58	2.25	2.00	1.58	1.58
Emotional Support	4.29	5.45	1.78	4.54	5.20	0.58	0.77
Venting	3.23	4.10	2.49	2.86	4.48	8.65*	1.12
Planning	5.13	6.25	1.51	5.25	6.13	0.91	0.47
Humor	2.68	2.90	0.13	2.43	3.15	1.38	3.08 ⁺
Acceptance	3.98	7.08	4.32 ⁺	4.73	6.33	1.15	0.40
Religion	5.70	6.93	2.31	6.70	5.93	0.91	0.02
Self Blame	3.25	3.68	0.32	3.38	3.55	0.05	0.19

n = 20

⁺*p* < .10. **p* < .05. ***p* < .01.

The 2 (Stage) x 2 (Gender) ANOVAs computed for each Cope subscale testing the effects of gender in the spouse's ability to cope with Alzheimer's disease identified two subscales providing significant findings. The venting subscale showed statistically significant results that spousal women ($M = 4.48$) utilized this coping strategy more than spousal men ($M = 2.86$), $F(1,16) = 8.65$, $p < .01$. The acceptance subscale findings provided a marginally significant difference between spouses whose partner had either mild or moderate AD. Those with spouses in the moderate stage ($M = 7.08$) used the acceptance strategy more than the spouses whose partner was in the mild stage ($M = 3.98$), $F(1,16) = 4.32$, $p = .054$. None of the results comparing the impairment level and gender interactions were significant.

Correlations. Table 7 summarizes the results of correlating each of the scales. A negative correlation was found between marital satisfaction and the use of humor as a coping strategy. Higher levels of marital satisfaction for participants was linked to lower use of humor, $r(40) = -.44$, $p < .01$. A significant negative correlation was also found between caregiver burden and marital satisfaction. Higher levels of caregiver burden correlated to lower levels of marital satisfaction, $r(40) = -.48$, $p < .01$. Caregiver burden was also found to correlate with three coping subscales. There was a significant positive correlation between caregiver burden and the subscales of venting, $r(20) = .66$, $p < .01$, planning, $r(20) = .47$, $p < .05$, and self blame, $r(20) = .51$, $p < .05$. A higher level of caregiver burden is linked to a higher use of venting, planning, and self blame coping strategies. The use of the coping strategy of seeking emotional support was positively correlated with the use of planning, $r(40) = .44$, $p < .01$ and acceptance, $r(40) = .53$, $p < .01$ coping strategies. Participants who utilized emotional support were more likely to use planning and acceptance as coping

Table 7

Correlations for Caregiver Burden, Dyadic Adjustment Scale, Cope, and Activities of Daily Living

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Caregiver Burden ^a	1.00											
2. DSS ^b	-.48**	1.00										
Cope Subscales ^b												
3. Substance Use	.16	.02	1.00									
4. Emotional Support	.40	-.15	-.01	1.00								
5. Venting	.66**	-.23	-.03	.09	1.00							
6. Planning	.47*	-.28	.14	.44**	.26	1.00						
7. Humor	.35	-.44**	.07	.15	.22	.10	1.00					
8. Acceptance	.41	-.10	.07	.53**	.22	.66**	.09	1.00				
9. Religion	.11	-.13	.11	.30	-.09	.48**	-.15	.27	1.00			
10. Self Blame	.51*	-.24	.04	.16	.34*	.33*	.24	.22	.36*	1.00		
11. ADL Spouse ^a	.24	.24	.02	.08	-.05	.29	.25	.19	-.09	-.15	1.00	
12. ADL Afflicted ^a	-.32	.18	-.04	-.48*	.06	.07	-.54*	-.08	.35	.19	.04	1.00

^a $n = 20$ ^b $n = 40$ * $p < .05$. ** $p < .01$

strategies as well. The use of the venting strategy was positively correlated with the use of the self blame strategy, $r(40) = .34, p < .05$. The more participants used venting as a coping strategy, the more likely they were to also cope through self blame.

The use of the coping strategy of planning was also positively correlated with the use of the acceptance, $r(40) = .66, p < .01$ strategy, turning to religion, $r(40) = .48, p < .01$ and self blame, $r(40) = .33, p < .05$. A higher use of planning as a coping mechanism was linked to a higher use of acceptance, religion, and self blame as a means of coping. The use of the coping strategy of self blame was positively correlated with turning to religion, $r(40) = .36, p < .05$. The more participants blamed themselves, the more they turned to religion to cope.

Two significant correlations were found for the afflicted spouse's Activities of Daily Living score. The two Cope subscales significantly correlated with the ADL were use of emotional support $r(20) = -.48, p < .05$ and humor $r(20) = -.54, p < .05$. The afflicted participant with higher ADL scores was less likely to use emotional support or humor as a coping strategy.

Results from the assessments provided both expected and surprising findings. In particular, marital satisfaction was found to be significantly different between the non-afflicted male and female spouses and gender differences were noted in the effects of caregiver burden and how participants coped. Women reported more caregiver burden and female spouses were more likely to use venting as a coping strategy. The next section provides results of the interviews. Supplementing the data with the interview material adds depth and insight into the previously reported findings.

Interview

The interview portion of the research provided an extension to the quantitative results gathered through the assessments. Participants were willing to provide insight into their experiences often drawing upon the information provided during the survey section. The guiding structure associated with the interviews produced three themes connected to cognitive decline experienced within a dyadic relationship. The themes were: current services utilized, important elements of the marital relationship that impact living with AD, and willingness for use of marital and family therapy. The next section addresses the first of the themes pertaining to existing services and the participants' impressions of how well they addressed their needs.

Current services. The participants expressed impressions of current services used, drawing from the experience of being diagnosed between two months and five years ago, all receiving the diagnosis from a neuroscience physician, and often with the experience of being afflicted with concurrent illnesses which included diabetes, leukemia, heart problems, arthritis, high blood pressure and cholesterol, asthma, and headaches. Table 8 summarizes the services that participants conveyed using at the time of the interview and information related to how the couples rated the services.

Table 8

Helpfulness of Services Couples Utilized

Service	<i>n</i>	Minimum	Maximum	<i>M</i>
Memory Clinic	10	1.0	10	6.05
Internet	9	1.5	9	4.56
Alzheimer Support Group	2	9.0	10	9.50
Adult Day Care	1	9.0	9	9.00
Counseling	0	0.0	0	0.00

Note. Services were rated on a 10 point scale (1 = not helpful , 10 = very helpful).

The resource utilized by more participants for information about AD, other than use of the memory clinic, was the internet. Participants reported visiting websites such as the Alzheimer's Association website and using general search engines such as Google to find information. Reports on the level of helpfulness seemed to depend on the amount of acceptance of the diagnosis and how the websites visited conveyed the information. Some reported optimism at being more informed, whereas others reported anger and pessimism. An example of such reaction was provided by Mrs. R when asked whether the couple used online resources stating:

At this stage I become angry and depressed with it, but yes I go online and I've read quite a bit about it. But right now I don't want to read about it. I'm not closed minded about it but right now I'm angry with it (the diagnosis).

Such a reaction is an example of the coping mechanism of denial and avoidance.

The Alzheimer support group and adult day care services were rated very highly by both the afflicted and their spouses but only utilized by a small number of participants. Of those who utilized these services it was apparent that they recognized the benefits of such

specific resources dedicated to their specific situation. The spouse of Mr. B provided an example of this benefit, stating:

It's (adult day care) a very good thing because I still work. We all know that he's safe and we all know that he gets a good lunch. They do things there that he would do at home by himself, and now there's interaction with other people."

Unfortunately, the participants citing the support group and adult day care services as very helpful also reported they no longer used these resources because both resources had been disbanded. These services were the only ones reported during the interview to have been used in the past but no longer used.

Important relationship elements. The second theme emerged when couples were prompted to discuss services and resources that had somehow impacted their marriage. Through the question, "What services/resources do you feel have specifically strengthened your marriage?" it was found that couples relied on more than services provided through the medical and social services fields to keep the relationship strong. The theme that emerged related to the strengths that had developed over time as a married couple. The element of longevity through spending many years together provided a foundation for couples to use when making decisions and coping with changes. Also under this theme, couples cited specific elements such as sharing recreational activities, marital vows, shared religious participation, optimism, patience, and acceptance and appreciation of one another. Mr. and Mrs. K related that:

Part of it is a give and take; you can't have it all your way. You've got to give to the

woman or man half the problem. Everybody is an individual. It takes two to make things work. If the other doesn't want to or isn't able to give then it isn't going to work for very long.

Simply stated, this example provides a feeling for the wisdom that develops over the length of a relationship. The specific recreational activities mentioned that the participants shared were golfing as a team, engaging in community events together, and as Mr. P stated, "anything that will provide stimulation to both my wife's mental state and our relationship." A shared religious participation included both the elements of physically going to church together and engaging in the activities there, and as being spiritually invested in a similar belief system. Couple R related that there was something very helpful in dealing with something as straining as AD when they share a common belief about how to approach the situation.

Other important elements reported as having an impact on the strength of the marriage included family support, use of the memory clinic, having a diagnosis, and the previously mentioned adult day care for respite. Family support was reportedly important because it allowed both the afflicted and the spouse to lean on others when they were unsure about the next step to take, and the family was able to provide emotional support and the chance to vent. The memory clinic and diagnosis responses connected as they supplied the common element of knowledge. The couples reported a general feeling of unity when knowledge was present, as it allowed them to make plans to approach the issue of cognitive decline together. With the knowledge that the memory clinic staff and the definition a diagnosis provided, couples were able to make more informed decisions about the future.

Use of MFT services. Couples were asked whether they would consider using marital and family therapy as a resource for coping with AD. The responses were promising and allowed insight into what therapists should be aware of in their approach. Sixty three percent reported they would consider using such a resource if the content was more focused on the memory issues and how to cope as opposed to addressing the state of the marriage. An example of this preference was provided by Mr. A, “we may have to (use therapy), if the disease progresses to where she becomes very hostile, we might use that as a resource.” This statement suggests the need for such a resource is present in order to provide guidance in adjusting to the symptom associated with cognitive decline. The other thirty seven percent who reported they would decline using this resource cited most often that they did not see a reason for it or that it was not needed at this point. It was observed that most who responded negatively to this service were of the mindset that their situation could not be changed in either marriage or affliction.

When prompted to expand on what the couples saw as potentially beneficial to address in therapy the responses aligned with the question concerning services/resources that were needed but were not currently available. Participants reflected it would be helpful to obtain more in-depth information and support for the changes associated with AD symptoms. Specific examples provided by participants included the desire for a memory class, help for the spouse about knowing what they are doing well and how to improve their support, and a more intensive list and understanding of what resources are available with reference to AD.

At the close of each interview, participants were prompted to express any general or summarizing thoughts on the issues discussed during the interview or in general. Participants often stated that they felt all was covered during the interview itself but some did provide

some important expansions. A great deal that came out of this closing question provides insight into how couples reacted to this life experience. One couple expressed that advertising seems such an important component to providing resource outlets to this disease and would like to see more. Many spoke of the future, noting that with an incurable affliction there is a struggle to find answers concerning AD. Many expressed that they were left to their own efforts to weather this transition. Such an expression does well to summarize the elements that were born of the interview process.

The interviews provided specific insight into what couples afflicted with AD already know about their options to cope with this disease are, and where professionals taking on the task of providing support still need to venture. There are many contributing factors in a couple's life that impact how they adjust to the diagnosis, and it is important to pay attention to the systemic way in which they affect one another.

CHAPTER 5.DISCUSSION

The purpose of this study was to investigate the possible therapeutic needs of those afflicted with Alzheimer's disease and their spouses. The study was conducted to expand knowledge about what couples at different stages of the disease experience and what resources they convey as necessary to help them through the experience. The outcome of this study provided an array of findings. Some conclusions were in line with the investigator's initial hypotheses, others were not. What follows is a discussion of how the initial aims of the study unfolded and what the results of the analyses and interviews indicated with relation to and in consideration of the current research surrounding couples and their experiences of Alzheimer's disease. Beyond the relationship of the current findings to past research, there will also be a discussion of the clinical implications of such findings and the study limitations.

The first aim of the study was to address the differences experienced by spouses dealing with AD when comparing those in the mild stage of AD and those in the moderate stage of AD. This aim was investigated through the assessment of marital satisfaction, caregiver burden, and coping to investigate whether differences existed between the stages of the disease.

The second aim of the study was to address the resources that already existed for couples and individuals dealing with AD and investigate their perceived benefits and drawbacks as communicated by couples who are currently living with AD. Such an aim was important to inform professionals with an interest in providing services to such a population in order to draw out whether voids still existed in resources. The following sections address

the findings concerning marital satisfaction, caregiver burden, coping and activities of daily living as they pertain to the aims of the study.

Marital Satisfaction

It was predicted that marital satisfaction levels differed significantly between those diagnosed with Alzheimer's disease and their spouses at different stages of the disease. It was also predicted that marital satisfaction differed between non-afflicted male and female spouses. The first hypothesis was not supported but results indicated that a significant difference existed between non-afflicted spouses according to gender. Female non-afflicted spouses reported a lower level of marital satisfaction than their non-afflicted male counterparts. Such findings suggest that the presence of AD does not significantly affect the perception of marital satisfaction overall but that there is some affect on the non-afflicted spouses concerning gender. It is possible that due to the low number of participants a significant difference does exist between stages but could not be detected.

Recent research indicates that men and women do in fact experience differences in marital quality, with women steadily experiencing an increase in marital strain over the later years directly affecting marital satisfaction whereas men generally even out in their perception of increased marital strain after age 60 (Umberson & Williams, 2005). The divergence cited for such variance in marital strain included the age difference, as women are more likely to experience the strain of an ailing older husband and due to the fact that men frequently experience illnesses at a younger age than women. This literature was supported by the findings of this study, but only between non-afflicted spouses. A study by Ott et al. (2007) using a similar form of the DSS to measure marital adjustment also did not find significant differences between men and women when all participants including the afflicted

were surveyed. The authors reported no significant difference between spouses of afflicted individuals and older couples not experiencing AD in marital satisfaction. The findings of the current study and those by Ott et al. (2007) suggest resilience in older couples even in the presence of a potential crisis event associated with cognitive decline. Argyle and Furnham (1983) found that older couples reported more satisfaction from their spousal relationships than younger couples and also noted less conflict than younger couples within the relationship. Such studies promote the argument that as couples age they are able to draw upon the experiences of longevity to maintain marital satisfaction.

Caregiver Burden

It was predicted that the level of caregiver burden was higher for women than men. Research supports that women are more often the spouse that assumes the role of household manager and caretaker for the family (Sollie, 2002). It was thought that there would be more burden as a result of adding to the roles women already occupied. The results of the ANOVA supported the original hypothesis, providing a statistical trend maintaining that women are reportedly more likely to experience a higher level of caregiver burden than their male counterparts. It should be noted here that there is the possibility that effect size played a part in the findings, as the means are very different between the two groups. The results follow a logical line of thinking if one considers the gender disparity in that women often own more household responsibility, filling the role of the person in charge of taking care of house and family. When one considers the implications of a woman adding the task of caring for a husband afflicted with AD and eventually assuming some of the roles her husband filled as well to her daily responsibilities, the picture for higher caregiver burden among wives

becomes clearer. Husbands are also more likely to receive help from adult children who assume the role of secondary caregiver to alleviate some of the burden (Miller & Guo, 2000).

Results of the correlation analyses concerning caregiver burden found three subscales that were significantly related to higher levels of burden. The three subscales were venting, planning, and self-blame. Cavanaugh (1998) noted that spousal caregivers of those experiencing AD had increased psychological distress due to a shift in the division of labor, shared responsibilities, and overall forced adjustments that occur to compensate for the symptoms of AD. Venting was also found to differ significantly in the ANOVA that analyzed only non-afflicted spouses finding that women used venting more than men as a coping strategy and thus providing support for a difference in how men and women deal with burden.

As women are socialized in our society to be more vocal about their feelings than men, it follows socialization that the venting coping mechanism was utilized a significant portion of the time in response to the burden of caring for one's spouse (Sheinberg & Penn, 1991). In other words, as women reported experiencing a higher degree of burden they reacted to such burden in a way that is socially accepted for women and thus the coping mechanism found to correlate significantly with the burden was associated with the female gender. Calasanti and King (2007) reported findings that men were more likely react to caregiver burden in ways that were socially acceptable such as blocking emotions and self-medicating to forget.

Results from the interview also informs the important implications of both having support for the burden experienced by AD spouses and what can happen if there is no support present. The services that rated highest on the helpful scale were those specifically designed

to address caregiver burden and provide respite. Alzheimer's support groups and adult day care were both cited as highly beneficial and although there were very few who spoke of using such services, previous research also supports the effectiveness of their use. Zarit, Johansson, and Jarrott (1998) reported that the spousal caregivers indicating the lowest levels of stress and overload were those who had a social support outlet *and* help with the task of caring for their spouse. When both elements were addressed, a higher level of well-being and a lower level of overwhelm were experienced. Such information also tells why couples cited family support and knowledge as important relationship elements. Those who spoke of family support cited having help from adult children and grandchildren. The use of other family members for respite and help in making decisions would provide a break for the spouse from constant responsibility. Knowledge informs couples of what to expect from the future as the AD progresses, thus allowing for couples to plan ahead and gradually transition roles once allocated to the afflicted spouse. If expectations are not laid out, it is possible that this is where some of the overwhelm Zarit et al. discussed could originate. Ott et al. (2007) found support for the importance of knowledge about the disease as well. Couples reported appreciation for such knowledge as it allowed for informed decisions to be made in preparation for the future.

There were many couples who cited no outside support services utilized beyond addressing medication options and guidance from the neuroscience physician. It is important to note the demeanor and experiences relayed by such couples. These couples were most often the participants who reported not wanting to turn to family for support for fear of burdening them and often relayed a much despaired take on living with AD. Such couples, it seems, would be at highest risk for caregiver burden. These were the couples who might

benefit most from outside services that incorporate a systemic view stressing the importance of finding support outlets and the implications if one does not utilize resources, such as a higher level burnout at a faster rate. If anything can be taken from the study by Zarit et al. (1998), it is the message that although emotional support and respite support are both important individually, they are not nearly as effective as when used in tandem. A systemic viewpoint would help to nurture such an outcome of using multiple resources and stressing their compounding effect on increased well-being.

Coping

The coping research set out to explore whether differences existed between spouses in the use of coping strategies of the afflicted versus non-afflicted spouses and whether there were any gender differences. Supportive results were found in the use of humor as a coping strategy. Those afflicted with AD were more likely to utilize humor than their spousal counterparts. The same was found for the use of acceptance as a coping mechanism, though results do indicate that those in the moderate category of cognitive impairment and their spouses used acceptance in a similar manner. This finding adds an important element to previous research which indicates that the use of acceptance as a coping strategy is related to lower depression in spouses facing cognitive decline of their partner (Zarit et al., 1998). Thus, increased use of acceptance at later stages of the disease may counteract depressive symptoms and in turn lessen the effects of burden placed on a spouse. Ott et al. (2007) noted that acceptance may also help spouses cope with the grief related to a partner's decline. Through the increased use of acceptance, a spouse can move from the emotion-focused coping skills that do not promote action to increasing one's involvement with change of the

situation. Ott et al. (2007) asserted that through increased acceptance and subsequently increased action there is increased potential for personal growth.

The paired *t*-test results did not uncover for any significant findings regarding religion but it is important to make note of this coping skill as it was used frequently by both spouses and mentioned often during the interviews as one resource couples utilized in maintaining marital strength. Religion is often an important factor in the decision to marry and marital satisfaction from the very beginning and so it follows that religion would continue to be something on which spouses aligned (Weaver, Koenig, & Larson, 1997).

The correlation findings within the subscales themselves provided mixed results. One body of coping research indicates that there are two categories in which most coping strategies fall (Fromholt & Bruhn, 1998). As previously discussed in the literature review, these two categories are problem-focused and emotion-focused coping strategies. Problem-focused coping incorporates action-oriented means of dealing with stressors and emotion-focused coping captures the means people use to feel better emotionally but do not involve action steps to eliminate the stressors. The problem-focused coping categories used in this study were planning and religion. Note that the planning questions focused on creating a strategy and thinking about what steps to take, and the religion questions encompassed turning to prayer or meditation and finding comfort in religious beliefs. Although such religious actions may seem more emotion-focused, upon further inspection and the finding that most participants were of Christian denomination, it is possible that the act of praying or relying on beliefs could be considered active coping skills with the hope that something would come of such actions as discussed by Carver (1989), the author of the Brief Cope (Carver, 1997). Although this particular piece of research is dated, it still holds value due to

the author's consideration that different religions experience prayer and meditation differently with varying expected outcomes. The other six coping strategies fall under the emotion-focused coping category as they all identify actions that do not change the situation but impact one's state of well-being. The six emotion-focused strategies are substance use, seeking emotional support, venting, use of humor, acceptance, and self blame.

The correlations that followed the concept of problem- and emotion-focused coping suggest a common group including strategies of acceptance and emotional support, religion and planning, and self blame and venting. The correlations that did not follow the concept of problem- and emotion-focused coping grouping were correlations between acceptance and planning, emotional support and planning, self-blame and planning, and self-blame and religion. The results indicate that people do not always use one coping style over another. It is likely that correlations between problem- and emotion-focused coping strategies are present because people utilize both, choosing to use those that fit their specific circumstances.

The categories of services presented during the interview portion further support the use of multiple resources of both emotion- and problem-focused coping strategies. For example, the couple that utilized the AD support group also used the adult day care, both providing a mixture of emotional support and problem-focused support. Drawing upon previous research it is also important to highlight the subject of religion and spirituality as it relates to coping. Research indicates that religion and spirituality becomes increasingly important as one ages, especially for many experiencing degenerative health circumstances as they are faced with mortality (Neidhardt & Allen, 1993). Many of the participants in this

study mentioned religion and religious participation as an important component to their relationship and well-being when facing the effects of AD.

The information revealed during the interviews also added important depth to what resources are helpful in the coping process and how such resources may be viewed at various times over the course of the disease. For example, one participant expressed feelings of anger and denial when utilizing the internet for information to research her own diagnosis but also stated that when she was caring for her mother who had AD the internet was a very helpful tool. Mrs. R's insight highlights the idea that different resources affect people in different ways at different times. From her experience, one can take that there are times when the afflicted might need different resources than their caregivers in order to cope with the disease.

Limitations of the Study

The research presented here is not without limitations. The course of gathering the data and the final number of participants was well below what is typically required for statistical analyses. The process of finding willing participants through the memory clinic was difficult at times due to participants missing appointments with the neuroscience physician and the limited number of potential participants who attended their doctor appointment with a spouse. The Institutional Review Board protocol was not approved for use with any other organization or group, nor was there approval to enter private homes as there was a chance that a legally authorized representative for a person not mentally competent to provide consent would not be in place when necessary. The Alzheimer's Association did not allow the researcher to advertise during support group meetings as the

meetings were structured to guarantee anonymity and allowing someone to come into such meetings would violate this structure.

The participant pool itself also presented some limitations. There was no ethnic diversity present in the participant pool, nor was there diversity in sexual orientation as the study focused on spouses in the legally recognized sense. Spiritual diversity was negligible. The participants were also limited to those still living in the community functioning at mild to moderate impairment. Nursing home residents with AD were excluded.

Perhaps one of the most important limitations to mention that could impact future research is that of the applicability of assessment scales used to study older couples. One such example is the applicability of the DSS to older couples. There is little research available concerning aging couples and their experiences of relationship satisfaction. It would be highly beneficial in future studies to determine if other means of measuring relationship satisfaction in aging couples who have been together for a majority of their life are necessary. Finally, it is important to note that this was an exploratory study with a limited sample that is not necessarily representative of all aging couples experiencing Alzheimer's disease. More studies with larger samples and a representative population would be advised in future research.

Along similar lines, it is possible that the CBI analyses found higher burden among women because the format of the questions resonate perhaps more with women. The questions begin with the phrase "I feel," thus setting up the question with an emotional connotation. If the questions were phrased differently, perhaps with an orientation to task, higher burden scores might be obtained from men.

Research Implications

It seems important at this point to mention some observed implications for working with this population for research purposes. It is possible that afflicted spouses may have difficulty understanding the questions, and it is important to maintain reassurance that there is no right or wrong answer. In this study, participants often looked to spouses for help. Researcher must be well versed in the ability to bolster participant confidence and deter participant interaction. Also, it is important to note that this investigator's clinical training had some impact on how the interview was facilitated. The investigator worked carefully to foster a comfortable and open atmosphere. The survey packets were also printed in larger font.

Clinical Implications

The information gathered during the process of this research project has provided many interesting findings that both support and expand on previous research about the experience of living with AD in a marriage. Findings indicated that more than half of the participants would consider using marital and family therapy to cope with the disease. What follows are the clinical implications of such findings that will inform the work of those interested in working with this population from a systemic couples perspective.

The first and seemingly most important clinical implication of the research findings is the need to be aware of the intricate nature of experiencing the onset of dementia as a couple. The findings indicate that there are parts of this experience that couples need similar support but there are also experiences that each spouse may need individualized attention in order to better suit their unique experiences. No two couples will require the same services, and neither will any two spouses. A clinician must be prepared to assess for such similarities

and differences initially and continue to revisit the assessment phase to appropriately track adjustment through the cognitive decline. For example, one participant expressed his concern during the interview that eventually he may need other support than what the couple is currently receiving to cope with the changes he may see in his wife's personality and demeanor. He expressed concern that increased hostility may force him to seek out professional counseling to receive guidance on how to better cope with such change.

The topic of a solid knowledge base is the next subject that seems important for clinicians to cultivate awareness. Knowledge includes not only an up-to-date understanding of current research related to dementia and the science behind the disease, but also an understanding of what resources are available in the community for couples to access in order to better deal with the disease. Participants of this study vocalized a desire for memory classes for the afflicted spouses and their partners and also someone to take the time to educate them directly about what to expect throughout the course of the disease.

The findings of this study showed that many couples used the internet to form an understanding of the disease and to research medication options. The internet can be a useful tool to increase knowledge but can also be an overwhelming experience. Someone to guide couples seeking information to the sites that are most informative and evidence-based was a real need for the participants. Other resources beyond the internet that clinicians should be aware of are available support groups, respite options, and qualified specialists. If such services are not available locally, a clinician may find it necessary to reach out to larger communities.

Previous research indicates that when older couples are aware of counseling resources they are in fact apt to use them as frequently as younger couples (Knight et al., 2006). The

issue of referral is where the problem seems to exist. As previously discussed, the primary care physician is often the gatekeeper to the mental health field. It is important for clinicians to cultivate positive and informed relationships with referral sources to increase clientele access. Such relationships may also be beneficial in providing an objective opinion about the referred spouse's current state of decline and where existing supports are already present for couples coming into counseling.

Clinicians may also provide benefit to couples through encouragement and assistance in planning ahead in order to decrease caregiver burden as the dementia progresses and to prepare other family members in the system for what to expect at certain points in the decline. Connell, Boise, Stuckey, Holmes, and Hudson (2004) reported finding a high degree of variability in preference among family members concerning disclosure of the disease to others. Planning with couples may include identifying the people in their support system to be counted on for certain activities of daily living. For example it may be beneficial to identify which adult children live nearest to the couple that may provide transportation and respite. Neighbors could be informed of the latest medical updates including cognitive status in order to watch for confusion and dangerous activities such as going outside in the cold without proper attire. Planning for financial implications may also be an important area to address with couples. If the afflicted spouse is the house accountant, it may be important to transition that role over to the spouse sooner rather than later.

Another important point drawn from the interviews with participants that may influence how successful clinicians are at drawing in and retaining clients is how couples are approached. Many couples who agreed they would consider using marital and family therapy stressed that one deciding factor was the content of the therapy. The participants emphasized

it was not the current state of their marriage that they desired help with, but rather the issues linked with the ongoing decline in health and mental state of the afflicted. In other words, clinicians should understand that couples are not coming into therapy to alter the state of their relationship from the perspective that there is something wrong with the bond but rather they need help in weathering this transition.

Yet another issue that arose from the results of the study that may have large impact on the therapeutic journey is that of how a clinician looks at gender. From the results and previous research one knows that there is a difference in marital satisfaction and caregiver burden between men and women. Women generally report lower satisfaction levels and higher burden levels than their male counterparts. Thus it seems very important that a clinician address the underlying narratives that may influence such differences. Such differences may include social experiences of the time in which the couple grew up and how this affects roles assigned to men and women, perceptions of the responsibility for one's spouse during illness, and the messages that one received growing up about asking for assistance (Maples & Abney, 2006). In a similar vein, clinicians may do well to understand how gender influences each spouse's means of coping. The findings of the study provided evidence that there are differences in how people choose to cope and research supports that the means by which one copes affects the outcome of not only one's health and well-being but that of the afflicted spouse (McClendon et al., 2004).

As stated earlier, religion/spirituality emerged as an important element for couples when facing AD. Such findings hold the important implication for clinicians that illustrates yet another element to the depth of the experience of AD. It seems vital that clinicians assess for and understand the extent that religion influences how a couple copes with the illness.

Although one may not find involvement with an organized religion during assessment, the experience of the diagnosis defines a mortality timeline. When faced with mortality it is probable that clients will wrestle with the issue of what this means for them and their family. In any event, clinicians should be aware of the presence of such personal thoughts and take time to decide whether they are equipped and comfortable with addressing this topic. If one finds that they are not comfortable, the issue again arises of the importance of having contacts in the community that is better suited with the task. Clinicians may benefit from familiarizing themselves with the different churches, synagogues, and mosques in the area.

The implications of this study for clinicians are many. The findings of this study provided insight into what older couples, especially those experiencing the effects of an incurable disease, see as important elements to address when seeking help and understanding outside the family. Perhaps the most important implication for clinicians to realize is that there are many directions in which to approach therapy with couples experiencing AD. They must be prepared to act as a confidant, resource guide, and interpreter for the medical world to provide effective therapy to these couples. As with any other couple, spouses have distinctive perceptions, emotions, and means of coping with dementia. It is not the age that should be focused on in this population. Rather, it is the issues unique to dealing with AD and how they are currently affecting the relationship that is important.

APPENDIX A. INSTITUTIONAL REVIEW BOARD LETTER

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office of Research Assurance
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

DATE: 26 October 2007

TO: Amber Joy Bergman
c/o Peter Martin, 1096 LeBaron Hall

CC: Peter Martin
1096 LeBaron Hall

FROM: Jan Canny, IRB Administrator
Office of Research Assurances

IRB ID: 07-357

Approval Date: 10 October 2007

Date for Continuing Review: 4 September 2008

The Chair of the Institutional Review Board of Iowa State University has reviewed and approved the protocol entitled: "Dyadic spousal experiences of Alzheimer's disease: Marital satisfaction, caregiver burden, and coping." The protocol has been assigned the following ID Number: **07-357**. Please refer to this number in all correspondence regarding the protocol.

Your study has been approved from **10 October 2007** to **4 September 2008**. The **continuing review date** for this study is no later than **4 September 2008**. Federal regulations require continuing review of ongoing projects. Please submit the form with sufficient time (i.e. three to four weeks) for the IRB to review and approve continuation of the study, prior to the continuing review date.

Failure to complete and submit the continuing review form will result in expiration of IRB approval on the continuing review date and the file will be administratively closed. All research related activities involving the participants **must stop** on the continuing review date, until approval can be re-established, except when necessary to eliminate immediate hazard to research participants. As a courtesy to you, we will send a reminder of the approaching review prior to this date.

Please remember that any **changes in the protocol or consent form** may not be implemented without prior IRB review and approval, using the "Continuing Review and/or Modification" form. Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office of Research Assurances website or available by calling (515) 294-4566, www.compliance.iastate.edu.

You must promptly report any of the following to the IRB: (1) **all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.

Upon completion of the project, please submit a Project Closure Form to the Office of Research Assurances, 1138 Pearson Hall, to officially close the project.

APPENDIX B. SURVEY INSTRUMENTS

Packet for Spouse

ID. _____

The Couples and Cognition Study

Amber Bergman
Dr. Mehrdad Razavi
Dr. Peter Martin

Hello and thank you for your participation in this important study. With your involvement we hope to gain a better understanding of your experiences in the presence of memory problems. Questions have been divided into four sections.

1. Some general background questions about you.
2. Some questions about your marital experiences.
3. Some questions about your caregiving experiences.
4. Some questions related to how you deal with stressful experiences.

Please let me know if you have any questions about the survey at any time. I am glad to help.

Please turn the page to begin.

Section 1

This section includes questions about you.

Demographic and Activities of Daily Living Questionnaire

Directions: Please answer each of the following questions about yourself

1. Age: _____
2. Gender: Male _____ Female _____
3. Ethnic Background:

_____ White/Caucasian	_____ Asian/Pacific Islander
_____ African-American	_____ Hispanic/Latino
_____ American Indian	_____ Other (please specify) _____
4. Marital status
 Amount of time married: _____ years _____ months
 Number of marriages _____
5. Years of Education Completed _____
 Highest degree completed
 - a) High school attended _____
 - b) High school _____
 - c) College attended _____
 - d) Associate's degree (2 years) _____
 - e) Bachelor's degree (4 years) _____
 - f) Master's degree _____
 - g) Doctorate degree _____
6. Occupation (if retired please indicate this and provide occupation prior to retirement): _____
7. Children in family:

	Gender	Age
1.	M F	
2.	M F	
3.	M F	
4.	M F	
5.	M F	

8. Income per year:

Less than \$10,000 _____	\$10,000-\$20,000 _____
\$20,000-\$40,000 _____	\$40,000-\$60,000 _____
\$60,000-\$80,000 _____	\$80,000-\$100,000 _____
Greater than \$100,000 _____	

9. Religious affiliation: _____

10. How would you rate your current health?

_____Excellent _____Good _____Fair _____Poor

11. How would you rate your spouse's current health?

_____Excellent _____Good _____Fair _____Poor

Activities of Daily Living Questions

12. Can you use the telephone...

- a. Without help, including looking up numbers and dialing
- b. With some help
- c. Completely unable to use the telephone

13. Can you get to places out of walking distance...

- a. Without help (drive own car or travel alone via taxi, bus, etc.)
- b. With some help (need someone to drive or accompany you)
- c. Completely unable to travel unless emergency arrangements are made for specialized vehicle like an ambulance

14. Can you go shopping for groceries or clothes (assuming you have transportation)

- a. Without help (can go shopping by yourself)
- b. With some help (need someone to go with you or shop for you)
- c. Completely unable to go shopping

15. Can you prepare your own meals...

- a. Without help (could plan and cook means yourself, if needed)
- b. With some help (could prepare some things, but not full meals)
- c. Completely unable to prepare any meals on my own

16. Can you do housework...
 - a. Without help (clean floors or room, do light housework)
 - b. With some help (can do light work, but need help with heavy)
 - c. Completely unable to do any housework on my own
17. Can you take your own medication...
 - a. Without help (take the right does at the right time)
 - b. With some help (able to take medicine if someone prepares it or reminds you to take it)
 - c. Completely unable to take your own medication
18. Can you handle your own money...
 - a. Without help (manage spending, pay bills, write checks, etc.)
 - b. With some help (manage day-to-day buying but need help managing spending, paying bills, writing checks, etc.)
 - c. Completely unable to handle money
19. Can you eat...
 - a. Without help (able to feed yourself completely)
 - b. With some help (need help cutting, feeding self some foods)
 - c. Completely unable to feed yourself
20. Can you dress and undress yourself...
 - a. Without help (able to pick out clothes, dress/undress yourself)
 - b. With some help
 - c. Completely unable to dress or undress yourself
21. Can you take care of your own appearance (comb hair, wash face)
 - a. Without help
 - b. With some help
 - c. Completely unable to maintain appearance yourself
22. Can you walk...
 - a. Without help
 - b. With some help from a person on with a walker, cane, etc.
 - c. Completely unable to walk

23. Can you get in and out of bed...

- a. Without help
- b. With some help (from another person or aid of some device)
- c. Completely unable to get in and out of bed, dependent on someone else.

24. Can you take a bath or shower...

- a. Without help
- b. With some help (need help getting in and out, need special attachments on tub or shower)
- c. Completely unable to bath yourself

<p>STOP. You have just completed section 1. Please proceed and continue to section 2.</p>

Section 2

This section includes questions about your marital experience.

Dyadic Adjustment Scale-Satisfaction Subscale

The following are questions concerning yourself and your current relationship. Please respond to them using the scales provided. If you are not sure if an item pertains to you or your partner, please estimate your answer. Please be as forthright as possible on all of your answers.

The following questions have different answers. Please read the questions and answers carefully. Please indicate below approximately how often the following items occur between you and your partner based on this scale:

- 0 = All the time**
- 1 = Most of the time**
- 2 = More often than not**
- 3 = Occasionally**
- 4 = Rarely**
- 5 = Never**

- _____ 1. How often do you discuss or have you considered separation or terminating your relationship?
- _____ 2. How often do you or your partner leave the house after a fight?
- _____ 3. In general, how often do you think that things between you and your partner are going well?
- _____ 4. Do you confide in your mate?
- _____ 5. Do you ever regret that you entered into this relationship (or lived together)?
- _____ 6. How often do you and your partner quarrel?
- _____ 7. How often do you and your partner "get on each other's nerves?"

Use the scale below for question 8:

- 0 = Never**
- 1 = Rarely**
- 2 = Occasionally**
- 3 = Almost Every Day**
- 4 = Every Day**

- 8. How often do you kiss your mate? _____

9. The numbers on the following line represent different degrees of happiness in your relationship. The middle point, "happy" represents the degree of happiness of most relationships. Please indicate below which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

Degree of happiness, based on the scale above (**please circle**):

0 1 2 3 4 5 6

10. Which of the following statements best describes how you feel about the future of your relationship? (Please circle the number)
- 5 I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
 - 4 I want very much for my relationship to succeed, and will do all I can to see that it does.
 - 3 I want very much for my relationship to succeed, and will do my fair share to see that it does.
 - 2 It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
 - 1 It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
 - 0 My relationship can never succeed, and there is no more that I can do to keep the relationship going.

<p>STOP. You have just completed section 2. Please proceed and continue to section 3.</p>

Section 3

This section includes questions about your experiences of caring for your spouse.

Caregiver Burden Index

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; use the scale as a guide. There are no right or wrong answers.

0	1	2	3	4
Never	Rarely	Sometimes	Quite Frequently	Nearly Always

1. Do you feel that your relative asks for more help than he/she needs?

0 1 2 3 4

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

0 1 2 3 4

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0 1 2 3 4

4. Do you feel embarrassed over your relative's behavior?

0 1 2 3 4

5. Do you feel angry when you are around your relative?

0 1 2 3 4

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0 1 2 3 4

7. Are you afraid what the future holds for your relative?

0 1 2 3 4

0	1	2	3	4
Never	Rarely	Sometimes	Quite Frequently	Nearly Always

8. Do you feel your relative is dependent upon you?

0 1 2 3 4

9. Do you feel strained when you are around your relative?

0 1 2 3 4

10. Do you feel your health has suffered because of your involvement with your relative?

0 1 2 3 4

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0 1 2 3 4

12. Do you feel that your social life has suffered because you are caring for your relative?

0 1 2 3 4

13. Do you feel uncomfortable about having friends over, because of your relative?

0 1 2 3 4

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0 1 2 3 4

0	1	2	3	4
Never	Rarely	Sometimes	Quite Frequently	Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0 1 2 3 4

16. Do you feel that you will be unable to take care of your relative much longer?

0 1 2 3 4

17. Do you feel you have lost control of your life since your relative's illness?

0 1 2 3 4

18. Do you wish you could just leave the care of your relative to someone else?

0 1 2 3 4

19. Do you feel uncertain about what to do about your relative?

0 1 2 3 4

20. Do you feel you should be doing more for your relative?

0 1 2 3 4

21. Do you feel you could do a better job in caring for your relative?

0 1 2 3 4

22. Overall, how burdened do you feel in caring for your relative?

0 1 2 3 4

STOP. You have just completed section 3. Please proceed and
continue to section 4.

Section 4

This section includes questions about your experiences of coping with stressful life events.

Brief Cope

Please think about what you generally feel and do, when events cause a lot of stress. Circle the answer that best represents the way you deal with stressful experiences. Use the table below as a guide.

1	2	3	4
I usually don't do this at all	I rarely do this	I usually do this a little	I usually do this a lot

1. I've been turning to work or other activities to take my mind off things.

1 2 3 4

2. I've been concentrating my efforts on doing something about the situation I'm in

1 2 3 4

3. I've been saying to myself "this isn't real."

1 2 3 4

4. I've been using alcohol or other drugs to make myself feel better.

1 2 3 4

5. I've been getting emotional support from others.

1 2 3 4

6. I've been giving up trying to deal with it.

1 2 3 4

7. I've been taking action to try to make the situation better.

1 2 3 4

1	2	3	4
I usually don't do this at all	I rarely do this	I usually do this a little	I usually do this a lot

8. I've been refusing to believe that it has happened.

1 2 3 4

9. I've been saying things to let my unpleasant feelings escape.

1 2 3 4

10. I've been getting help and advice from other people.

1 2 3 4

11. I've been using alcohol or other drugs to help me get through it.

1 2 3 4

12. I've been trying to see it in a different light, to make it seem more positive.

1 2 3 4

13. I've been criticizing myself.

1 2 3 4

14. I've been trying to come up with a strategy about what to do.

1 2 3 4

15. I've been getting comfort and understanding from someone.

1 2 3 4

1	2	3	4
I usually don't do this at all	I rarely do this	I usually do this a little	I usually do this a lot

16. I've been giving up the attempt to cope.

1 2 3 4

17. I've been looking for something good in what is happening.

1 2 3 4

18. I've been making jokes about it.

1 2 3 4

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

1 2 3 4

20. I've been accepting the reality of the fact that it has happened.

1 2 3 4

21. I've been expressing my negative feelings.

1 2 3 4

22. I've been trying to find comfort in my religion or spiritual beliefs.

1 2 3 4

23. I've been trying to get advice or help from other people about what to do.

1 2 3 4

1	2	3	4
I usually don't do this at all	I rarely do this	I usually do this a little	I usually do this a lot

24. I've been learning to live with it.

1 2 3 4

25. I've been thinking hard about what steps to take.

1 2 3 4

26. I've been blaming myself for things that happened.

1 2 3 4

27. I've been praying or meditating.

1 2 3 4

28. I've been making fun of the situation.

1 2 3 4

Interview Portion

1. When did you/your spouse first address memory loss with a physician?
Date: Month/Year
2. Who made the diagnosis?
3. Concurrent illnesses in addition to memory problems? Afflicted and spouse.
4. Please indicate any current services/resources that you are using to better cope with memory problems and rate the level of help they provide.

Not helpful 1 2 3 4 5 6 7 8 9 10 Extremely helpful

Support Groups _____ Helpful rating _____ Specify support group _____
 Adult Day Care _____ Helpful rating _____ Specify length of attendance _____
 Counseling _____ Helpful rating _____ Specify counseling type _____
 Online resources _____ Helpful rating _____ Specify resources _____
 Other (specify) _____
 _____ Helpful rating _____
 _____ Helpful rating _____
 _____ Helpful rating _____

5. What services/resources do you feel have specifically strengthened your marriage?
6. Would you consider marital and family therapy as a resource option? Why or why not?
7. Are there any services/resources you used in the past but no longer use? Please note reason for discontinuation.
8. Are there any services/resources that are needed but are not available to you? What kinds of unavailable resources would help you to cope with the memory problems?
9. Do you have any final thoughts about services/resources related to memory problems and your experiences?

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